

Newborn Screening Update

*Michigan Newborn
Screening Program*



Fall 2008

Volume 7 Issue 2

Announcements....

Newborn Screening Follow-Up Program *Family Day a Success*

The Newborn Screening (NBS) Follow-up Program hosted a Family Recognition Day at the Impression Five Science Center in Lansing on September 6, 2008 to launch its Parent and Family Network Initiative. This kick-off event was a success with 28 families of children diagnosed through NBS and a total of 130 family members participating in the day's events. Children of all ages enjoyed hands-on activities and workshops at the Impression Five Science Center while their parents received education and support from other families and exhibitors from various MDCH programs, support services and medical management clinics in Michigan. There were 33 MDCH staff and exhibitors on hand who interacted with parents and children with medical disorders. The NBS Follow-up Program looks forward to the growth of the Parent and Family Network Initiative and future events emphasizing the importance of the short- and long-term follow-up in the care of these children and families.

Saturday NBS Specimen Pick-ups

Saturday testing began on June 21, 2008. This and other expanded services were required as part of recommendations by the MDCH Newborn Screening Quality Assurance Advisory Committee that went into effect March 2007. MDCH is now providing state paid pre-printed UPS labels which can be used for prompt Saturday pick-ups and delivery of your NBS specimens to the MDCH NBS Laboratory. See page 3 for more information on how to receive the valuable time-saving pre-printed labels and how Saturday testing and early diagnosis is saving lives.

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Fall 2008

• **UPDATE - NBS Hospital Coordinator Regional Meetings**

The newborn screening follow-up program resumed its educational activities at birthing hospitals. These are conducted as neonatal meetings across the state of Michigan to thus enhance the information sharing not only among NBS coordinators but also between them and the NBS program staff. The first NBS Hospital Coordinator meeting for the Central Michigan Region took place on September 24, 2008 at Sparrow Hospital in Lansing. NBS coordinators from nine birthing hospitals from this Region were invited to this meeting hosted by the MDCH NBS Follow-up Program. The follow-up education and coordination activities provided valuable information and tools for NBS coordinators. Guest speaker, Robert Conway, M.D., Director of the Biochemical Genetics Clinical Program at MSU presented a very informative lecture on Lysosomal Disorders. The NBS coordinators received valuable tools which included the Clinical Laboratory and Standards Training Manual and Video along with the Michigan Birth Defects Tool Kit.

The next NBS Hospital Coordinators regional meeting is scheduled for January 29, 2009 at Spectrum/ DeVos Hospital in Grand Rapids for Western Michigan hospitals. Newborn screening coordinators from 17 birthing hospitals will be receiving registration materials this month. If you have questions, please contact William Young at 517-335-8938 or Carole Flevaris at 517-335-8959.

• **IMPORTANT UPDATE - Cystic Fibrosis Screening**

Cystic Fibrosis (CF) is a chronic inherited disease that affects the exocrine glands of the lungs, liver, pancreas and digestive system. A defective gene and its protein causes the body to produce a thick, sticky mucous which clogs the lungs leading to serious lung infections and can inhibit the pancreas from the production of digestive enzymes for nutritional benefits. CF causes progressive health problems, shortened life-span and requires treatment. Early diagnosis of CF and intervention is critical. Over one thousand new cases are currently diagnosed in the United States each year. Screening for CF began in Michigan on October 1, 2007.

The Michigan Department of Community Health Newborn Screening Laboratory uses a two tier screening approach for the detection of CF. The first test measures trypsin, an enzyme produced in the pancreas that is transiently elevated in the blood of pancreatic insufficient CF patients at birth. This test is known as the immunoreactive trypsinogen (IRT) test. If the initial test is positive, then a DNA screening test is done to detect CF related mutations. Newborns with both an elevated IRT and an identified CF mutation are then referred to the CF Center for a sweat chloride test.

Newborns with meconium ileus, the intestinal obstructive variant of CF, which is the first sign of CF in 15 to 20% of newborns, may not have an elevated IRT at birth. This finding should lead to definitive sweat chloride testing regardless of the newborn screening results. Because newborns with meconium ileus may be negative on the IRT Screen, the newborn screening program should be notified whenever there is a newborn with meconium ileus identified in the nursery. The MDCH Newborn Screening Laboratory will then test for CF mutation regardless of the the IRT test results. Please share this information with your staff.



• **IMPORTANT UPDATE- Saturday Testing**

Recently, due to the new Saturday screening protocol, two infants benefited from quick diagnosis and treatment. The receipt of two newborn screening specimens, at the MDCH NBS Laboratory from two metropolitan hospitals contributed to the early diagnosis and treatment of PKU and Argino-succinic Acidemia (ASA), amino acid disorders. Without early diagnosis and treatment, the disorders could have contributed to significant health issues for the infants as in the case of ASA. Hospital staff were able to locate the infant and arrange for immediate admission to the hospital neonatal unit where the infant received immediate care by the Children's Hospital, Metabolic Clinic staff. The PKU infant likewise benefited from early intervention. Saturday testing and follow-up has confirmed that the earlier an infant receives treatment for NBS disorders the better the outcome. See NBS letter on page 6 regarding Saturday testing.

It has been noted that the mail rooms or shipping departments of the majority of hospitals are closed on Saturdays. This lends to hospital staff being responsible for the mailing of specimens to the MDCH laboratory. Often specimens drawn during the afternoon and evening on Friday are not picked up or mailed until Monday morning. In an effort to address this issue, the NBS Follow-up Program has contracted with both Quest Diagnostics and UPS Courier Services for Saturday pick-up of NBS specimens. If you do not have courier service, we recommend that you contact the Newborn Screening Follow-Up Coordinator, Carole Flevaris at 517-335-8959. At that time you will be provided with pre-printed UPS labels and instructions for contacting UPS for prompt Saturday pick-up at your site. This will require that you develop a protocol within your department for the additional utilization of courier services on Friday and early Saturday morning for NBS specimens.

• **IMPORTANT NEW ITEM- Information on Deceased Infants**

On occasion, when matching algorithms with birth certificates we find infants with no newborn screening blood specimen in the state NBS system. It would help significantly if NBS coordinators would regularly provide information to the state NBS Follow-Up Program regarding deceased Infants. Providing the NBS Program with this important information saves valuable time and energy for both hospital personnel and NBS coordinators. Without this information NBS Follow-up staff have to needlessly contact NBS hospital coordinators to follow-up on the missing NBS blood screen. Providing this information would eliminate the need for contacting bereaved parents regarding missing NBS blood specimens. We encourage you to incorporate into your protocol the ongoing calling, faxing or emailing names of deceased infants to the MI NBS Follow-up staff.

NBS Quality Assurance Information

- **Parental Refusal Form**

If a parent should refuse the newborn screening, please fax a copy of the signed Parental Refusal Form your institution uses to the NBS Program at 517-335-9419 or 517-335-9739. Missed NBS cases are found if there is a Newborn Hearing Screen and a Michigan birth certificate but there is no matching NBS blood specimen in the NBS database. If the NBS Program had the parental refusal form on file, we would know not to contact your institution about getting a family to return for a missed newborn screening blood test.

- **Early Specimens and Corrections**

Just a reminder on Early specimens, drawn at < 24 hours. At the bottom of the Early Letter Notice there is an area to correct the Birth Date, Time and Collection Date and Time information. If the information was filled out incorrectly on the specimen card submitted, please correct the information (please see page 5 for example). The majority of the time corrections save the baby from being poked again unnecessarily. Please do not send detailed pages from the medical record with this information.

- **Importance of Filling Out Newborn Screening Cards Correctly**

We ask that you please remind staff of the importance of filling out the newborn screening card completely and accurately. Incomplete or incorrect data entry, not using military time and entering data in the wrong fields on the specimen card are costly errors. Double check Birth Date/Time, Specimen Date/Collection Time, Physician contact information and all other required information to avoid time consuming errors that could delay reporting out a positive result. See information on pages 7, 8 and 9. Please refer to our website www.michigan.gov/newbornscreening for these helpful tools your staff can review: [Instructions for completing the Newborn Screening card](#), the [Newborn Screening Specimen Collection Presentation](#), and the [Newborn Screening Program Presentation](#).

- **Newborn Screening Card and Brochure Ordering**

For ordering purposes the office that handles newborn screening cards and brochures will be closed on these upcoming state holidays: December 24, 25, 31 and January 1, 2009. Please order in advance to avoid delays.

Midwives may obtain the pre-paid and pre-printed UPS mailing labels for specimens when ordering NBS screening cards and brochures. NBS specimens may be placed in UPS drop-boxes for prompt courier delivery to the MDCH NBS Laboratory.

Note—The contact person for newborn screening card / brochure ordering is NBS Accountant Valerie Klasko at (517) 241-5583.



Newborn Screening Program

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Lansing, MI 48909

Phone: (517) 335-9205 Fax: (517) 335-9419
Email: mdch-newbornscreening@michigan.gov
Website: www.mi.gov/newbornscreening

FACSIMILE TRANSMISSION ONLY

July 31, 2008

EARLY SPECIMEN* NEEDS PHYSICIAN REVIEW

Dear Doctor,

The newborn screening specimen obtained from this infant identified on the newborn screening card as your patient, was collected when the infant was less than 24 hours of age. This causes some of the test results to be inconclusive.

Baby:	Accession #:	Kit Number:
Birth Date:	Specimen Type:	Medical Record:
Collection Date:	Gender:	Gestation: wks
Collection Age:	Weight: grams	NICU:
Birth Order:	TPN:	
Birth Facility:		
Mother Name:		Phone:

Physician:	Phone:	Fax:
Submitter:		

If the infant is NOT in the NICU / SCN	If the infant IS in the NICU / SCN and birth weight => 1800gms	If the infant IS in the NICU / SCN and birth weight <1800gms
Call the parents and inform them of the early specimen. A second newborn screen should be obtained on a pink repeat specimen card. The repeat newborn screen can be collected at the delivering hospital or nearest outpatient laboratory and should be forwarded to the Newborn Screening Laboratory ASAP	If on TPN and/or Transfusions repeat newborn screen >72 hours after TPN and/or Transfusions discontinued. If not on TPN and/or Transfusions repeat newborn screen ASAP	Follow NICU protocol for obtaining repeat specimens at 14 and 30 days of age (or upon discharge). If the infant is positive for any disorder please follow instructions as directed on the positive report. If the infant receives continuous transfusion and/or TPN during the first 30 days, a repeat specimen should be obtained 72 hours after discontinuing transfusion and/or TPN and at 90 days post transfusion. Alternatively, if there is a 72-hour window of opportunity during the first 30 days that the infant is not being transfused or receiving TPN, the post-72 hour repeat specimen should be obtained. This specimen would be in place of the 14 or 30-day specimen whichever is closer. The 14-day post transfusion specimen would still be required.

***Note: If your records indicate this specimen was collected at => 24 hours please provide the following information and fax back to 517-335-9773 so that we may correct our records on this infant.**

Birth Date: _____ Birth Time: _____ Collection Date: _____ Collection Time: _____
(Military) (Military)

CONFIDENTIAL

The information contained in this fax/print-out from the Michigan Department of Community Health, Newborn Screening Program is confidential in nature. It is for the sole use of the subscriber named on the report(s). If you are not the intended recipient, you are hereby notified that any disclosure, distribution, copying or the taking of any action in regard to the contents of this report(s) is strictly prohibited. If you have received this report(s) in error, please telephone us immediately at (517) 335-9205 so that corrective action and destruction or return of the document(s) can be arranged.
DCH-1272 (07/05) (W)



STATE OF MICHIGAN

DEPARTMENT OF COMMUNITY HEALTH
LANSING

JENNIFER M. GRANHOLM
GOVERNOR

JANET OLSZEWSKI
DIRECTOR

June 2008

Newborn Screening Program Adds Saturday Testing
Start Date : June 21, 2008

Dear Practitioner:

We would like to inform you that the Newborn Screening (NBS) laboratory will begin Saturday testing on June 21, 2008.

These and other expanded services were required as part of recommendations by the MDCH Newborn Screening Quality Assurance committee that went into effect March 2007. (Note: Senate Bill 794 amended the 1978 Public Act 368 by adding sections 5430 and 5432).

Initially the disorders that will be tested for are Congenital Adrenal Hyperplasia (CAH), Galactosemia (GALT) and those metabolic disorders diagnosed via Mass Spectrometry (Amino Acids, Fatty Acid Oxidation and Organic Acids). Other disorders will be added at a later date (timeline to be determined).

Any positive results (Strong or Borderline) will be reported out on Saturday. For Strong positives you will also be contacted by the medical management centers designated by the Michigan Department of Community Health and thus involved with the disorders mentioned above. These centers are: Endocrine Follow-up Program at University of Michigan for CAH and Children's Hospital of Michigan Metabolic Clinic (CHMMC) for GALT and the disorders diagnosed via Mass Spectrometry. As some of the disorders will need immediate follow-up, it is important that your voice mail instructions are clear as to how the medical management center can locate the responsible primary care provider or on-call physician in your practice on the weekend.

As during the week, the positive reports will be faxed to the physician's office recorded on the newborn screening card. We ask that your fax machines be left on over the weekend. Two attempts will be made to fax the reports and if they should not go through they will be held until Monday morning and re-faxed at that time.

If you have any questions or concerns, please do not hesitate to contact us at (517) 335-9205 or by e-mail at mdch-newbornscreening@michigan.gov

Sincerely,

William Young, PhD
Manager, Newborn Screening Follow Up Program

DCH-1272 (07/05) (W)

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STATE OF MICHIGAN

DEPARTMENT OF COMMUNITY HEALTH
LANSING

JENNIFER M. GRANHOLM
GOVERNOR

JANET OLSZEWSKI
DIRECTOR

To: Michigan Birthing Hospital Coordinators

From: State Newborn Screening

Re: Changes in the First and Repeat newborn screening cards

New/changed fields on **First** cards are:
NICU / SPECIAL CARE?

New/changed fields on **Repeat** cards are:
NICU / SPECIAL CARE?
INFANT'S AGE (hrs) - this field has now been deleted
INFANT'S BIRTH WEIGHT (gms) - this field has now been deleted

On both the First and Repeat cards for

1. NICU / SPECIAL CARE?

If baby is not in NICU or Special Care unit please mark **NO**. If baby is in NICU please fill in the **NICU oval**. If baby is in Special Care unit please fill in the **SP CARE oval**

On the Repeat cards

1. The following fields have been deleted:

INFANT'S AGE (hrs)
INFANT'S BIRTH WEIGHT (gms)

BABY

MOTHER

PHYSICIAN

SUBMITTER

BIRTH HOSPITAL
 (if different from submitter)

LOT
 W071
 6903708

Use By 2011-04

LAST NAME _____ FIRST NAME _____
 BIRTH DATE _____ BIRTH TIME (Military) _____ BIRTH WT. (gms) _____ WKS GESTATION _____
 SPECIMEN DATE _____ COLLECTION TIME (Military) _____
 MEDICAL RECORD # _____
 Collected By: (initials) _____
 ANY TPN FEEDING? NO YES
 NICU/ SPECIAL CARE? AN RBC TRANSFUSION? YES DATE _____
 NO NICU SP CARE
 SINGLE BIRTH _____ MULTIPLE BIRTH → A B NO
 C D YES
 BIRTH ORDER ANTIBIOTICS?
 GENDER _____
 MALE _____
 FEMALE _____

LAST NAME _____ FIRST NAME _____
 ADDRESS _____
 CITY _____ STATE _____ ZIP _____
 PHONE _____
 SOCIAL SECURITY NUMBER _____
 BIRTH DATE _____
 MEDICAL RECORD # _____
 HEPATITIS B SURFACE ANTIGEN (HBsAg)
 TEST DATE _____ RESULT _____
 POSITIVE
 NEGATIVE
 MOM/BABY STEROID TX? NO YES

LAST NAME _____ FIRST NAME _____
 PHONE _____ FAX _____
 SUBMITTER NAME _____
 ADDRESS _____
 CITY _____ STATE _____ ZIP _____
 HOSPITAL CODE (if applicable) _____
 00

FIRST SAMPLE

MDCH USE ONLY

MI Dept. of Comm. Hlth.
 By Authority of Act 568
 P.A. MCLA 333.5431



We invite you to share positive experiences, suggestions and other NBS highlights in our newborn screening newsletter.

Please contact Carole Flevaris, Ph.D. at 517-335-8959

*Michigan Newborn
Screening Program*

201 Townsend Street
Lansing, MI 48913

Phone: 517-335-9205

Fax: 517-335-9419

Email: mdch-newbornscreening@Michigan.gov

Please complete the questionnaire below so that we may update our records to serve you best. Fax to 517-335-9419 or 517-335-9739

Name

Title

Hospital or Institution

Address

Email

Phone

Fax

I prefer to receive a hardcopy of the NBS Newsletter_____

I prefer to receive an e-mail copy only_____

NBS Screening & Follow-up topics that I would like to learn more about are:

1 _____

2 _____

3 _____

4 _____